

COMMUNICATING TOGETHER

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AS ABILITIES CHANGE

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The Ripple Effect

PAUL MARSHALL
GEB VERBURG

When we think about a ripple effect we possibly think of something or someone having the power to make a change that affects the masses. Wars can have ripple effects and so can births. This issue features articles about a generation of people born in a relatively short span of time, one of the lesser known ripples, a phenomenon that could be called "the late boomers". Welcome to our September Issue of **Communicating Together**. In addition to discussing the generation born between 1960 to 1966 which has been labelled Generation X, we are including several articles which we were unable to include in our June and March issues, due to space limitations. Family related articles are evident in the *Teaching and Learning* section which features Victor Valentic's survey for parents, in Shirley McNaughton's Perspective as she looks back on two special birthday parties and in Alda Stepran's article re families and parenting in Latvia.

As well as pinning down Generation-Xers by the facile expedient of a set of dates and a population cohort of a certain size and (questionable) purchasing power, we want to portray what we see as GenXistence, the worldview of a generation that to us is more telling than the stats. The literal age range is from 30 to 36; the effective range begins at 15. The world has become a shrinking, budget cutting, downsizing universe.

Education has lost its magic ability to uplift the masses. Churches are emptying. Universities are clogged with deadwood. We have a society without jobs and what jobs there are, are jobs without future. Gen-X means living in this world that is shoulder-deep in debt and deadly polluted by earlier generations that do not appear to worry about either and do not need to, during their lifetime.

That is how Geb sees Gen-X's inheritance and it is indeed not an enviable one. Futurelessness. In the words of Douglas Coupland, author of the book that bears the title *Generation X: Tales for an Accelerated Culture* (1991): "Our systems had stopped working, jammed with the odor of copy machines, white-out, the smell of bond paper, and the endless stress of pointless jobs done grudgingly to little applause." Coupland says about parents: "I want to tell them that I envy their upbringings that were so free of *futurelessness*. And I want to throttle them for blithely handing over the world to us like so much skid-marked underwear.

In their book, *Boom, Bust and Echo: How to Profit from the Coming Demographic Shift* (1996), David K. Foot with Daniel Stoffman look at the generations from a numeric and economic perspective. Gen-X, for them, is the tail end of the Baby Boomers who because of the accident of having been born at the end rather than at the beginning of a massive postwar birth wave, find resources stretched to the utter limit, jobs scarce, house prices plateauing just out of reach, with the looming obligation of having to pay for the retirement of the earlier and more well-off boomers.

There were 2.6 million people born between 1960 and 1966, a number which will have major effects on how they and we interact and live. We think of it as a hard packed path on which 2.6 million people are trying to travel. We both remember growing up on farms, where there were tractor paths around the farm which our dads just forgot about when it came to planting because the ground was so hard packed, they knew that it was unwise to try to produce a crop on that soil. Gen-X'ers do not even have that choice; their whole world is a tractorpath packed down by the first waves of baby boomers. They have very little choice and there is no room for those individuals who would benefit from more freedom to develop their own horizons. The boomers have stamped the footpath of life down so hard that it becomes difficult for Gen-Xers to plant and nurture new plants — new hopes, dreams, visions and new beginnings. We are living in an age where many countries are shoulder deep in debt and the general public appears not to worry about the coming generations because they either don't fully appreciate the threat or don't see it as a danger to themselves. As you well know both of us are persons who believe there always is room to create a life of quality, if one really wants it. Our fear is that we are dwelling too much on how Generation-Xers have it so difficult and it is blinding us to the many alternative ways to be a happy contributor in our community. Sure, from a demographic and a sociological view point, the perspective of Foot and Stoffman, we can learn a lot about forecasting the needs of our commu-

nities. As Generation-Xers go through their life stages, pursue an education, get jobs, get married, have families, and grow old, they will have to fight the packed earth of their oft trodden world and will have to create new ways of living, simply because the old ones are either worn out or filled up.

Demographers can predict pretty much what education, employment, housing, health and other needs will arise at different times as Gen-X'ers age. Why we or they "fail" to "make it out there" does not just depend on stats or numbers. We believe that there are alternatives. Nola appears to have found one such alternative and suggests a number of other ways in which we could help people who are going through a Gen-X depression. Geb also is more hopeful than usual in his column. We hope you will enjoy the perspectives on Generation X presented in this issue of **Communicating Together**.

We think Nola's personal testimony speaks volumes about a kind of a war that can overtake any human spirit in a very short order. When anything comes and puts our lives and our own identities in question, depression and worry come in and feed on each other, crushing who we are. It hurts and the wounds can go unseen for a lifetime. Some just don't make it through, still others make it through but they are very bitter. Slipping into a depression is a very real part of being alive. When our lifestyles are somehow in question, we need to find a way to nurture new ones and find the inner strength to move on. Nola was given the support to develop new and different paths for herself, just like many in the Generation X group, but it overflows

and touches all of us. Nola stated that she wonders if other AAC users and/or disabled people experience the same feelings as the person of Gen-X. Is Generation X a global thing that goes beyond any physical limitations and/or any culture barricades? Our guess is yes. Nola ends her article with a major question that we agree with her fully in asking. Are we as professionals and older AAC Users giving false hope to young disabled children, or are we training these children how to cope in a world in which they might not get a fair shake? Her article is very powerful.

Suzanne Clancy, in her *Perspective*, tackles the Gen-X issue straight by the horns and with the benefit of a historic perspective places Gen-X's woes on a parallel with the outlook of earlier generations of young people that were exposed to epidemics, postwar or prewar depression and their associated hard times. We find her contribution to be a healthy antidote to wimpyness, although we do believe that the barriers against which Gen-Xers rail are of a serious and daunting nature. Suzanne, like Paul, is optimistic regarding the opportunities that are simultaneously available to the Gen-X population. It is true that there is a lot of new technology and a totally new (and still relatively untrodden) path (cowpath, tractorpath)—namely the information highway that is opening up for all Gen-Xers as long as they can get access to a computer. Shirley McNaughton offers us a reminder of the strength to all members that comes from a family unit that bonds together in supporting a person with a disability.

We would like to wish our newest editor, Tracy Shepherd, all the very best in her new life following her marriage in September. We greatly appreciate the gifts that Tracy offers to us at **Communicating Together**.

And we extend a special thanks to Rob Haaf, for establishing **Communicating Together** on the World Wide Web. There are many exciting possibilities ahead now that we have "**ComTog Online**"!

ISAAC, 1996

Paul was at the International Society for Augmentative and Alternative Communication (ISAAC) conference, which was held in Vancouver, British Columbia in August. The feeling of a homecoming was very strong, over the four-day event. It was a time of renewing friendships and entering into new ones. It also was a time to teach and to learn. Two of the many highlights were: the Words Plus Lecture which was given by Michael Williams and the Don Johnson Incorporated - ISAAC Distinguished Lecture which was presented by Janice Light. Words can't describe these two wonderful lectures. We all were greatly blessed by the visions and the overflowing knowledge that these two incredibly gifted individuals gave in their presentations.

References:

Coupland, D. (1991). *Generation X: Tales for an Accelerated Culture*. New York: St. Martin's Press.

Foot, D. (1996). *Boom Bust & Echo*. Toronto: Macfarlane Walter & Ross.

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Is it any different for AAC users?

NOLA MILLIN



Nola Millin

In preparing to write this article I did some reading about this Generation X. Most of what I found described Generation-Xers to have the feeling of meaninglessness and to be prone to depression. Those characteristic don't make this generation look too good. Although I was born in the last portion of the Baby Boom era, I think what I have gone through this past year is typical of Generation-Xers. It has made me wonder if other AAC users and/or disabled people experience the same feeling as the people of this generation. Maybe we are not so different from the "average" individual after all.

Up to a few years ago I was in school part time so my life was pretty busy. I was either reading, doing assignments, or working on an essay. After I graduated, I seemed to get involved in a lot of committees. I travelled to Toronto once a month to attend meetings. My life was full of activity. Suddenly one day last summer, I had nothing to do. People would probably think that it was a welcomed break. Well, it wasn't. I began to slip into a depression.

During my worst times I got physically sick. I couldn't keep anything down. The doctor put me on medication to help combat the problem. The medication helped in the physical sense but I still had to deal with the emotional level. At that point, I thought my life was meaningless. All the committees I sat on washed up due to funding cuts. I wasn't doing anything with my life. I was experiencing the feelings of Generation X. I had gone to university but couldn't get a job and I was bored. People would tell me that I had a lot to offer yet there wasn't anyone taking my offers. My depression lasted for about four months. At my worst, I wanted to commit suicide. It frustrated me that I was disabled and would need help to kill myself!

Fortunately, I sought help for my problems and got back on the right track. I have a strong Christian belief so that helped. I had to re-think how I would spend my free time. Most people would love to have free time but I had too much. With help, I managed to figure out how to use my time wisely. I keep active by reading and doing some new committee work. Since the new year, I have been employed at a workshop for disabled adults. I edit their newsletter and do other manual labour jobs. Even though I'm only working 2 days a week, it's still enough to give me something to do. I enjoy the contact with the other workers. Having gone through depression and the feeling of life being meaningless has left me wondering how many others have experienced this or are experiencing it right now.

I know in my own life, I was raised to believe that once I had my university degrees I would get a job

and "live happily ever after." Reality is that jobs are difficult to come by for someone with my physical needs. The only reason I can work at the workshop is because there are people there who provide attendant care. Are we giving false hope to young disabled children, especially AAC users, by saying a device is the answer to their problems? The answer is, I don't know. My heart goes out to people with disabilities who are looking for opportunities to contribute to their society. I know what it's like to have the desire to be a part of society but not be able to find the right place to go. I wish professionals would train children on how to spend their leisure time because one day these children will be adults with free time. You can feel awfully lonely especially if you live alone like I do. Like the Generation X people, I have experienced meaninglessness and depression. They are not fun things to have gone through but I'm glad I did. I appreciate the apathy that Generation-Xers have. I think it's not that their life is meaningless, it's that they don't have anything to care about. Individuals with or without disabilities need to feel needed and have something to occupy their time. §

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A Generation-Xer Speaks Out!

PAUL DUNCAN KEEN

We thank Paul Keen for giving us permission to reprint a Letter to the Editor which he wrote to The Spectator, Hamilton, Ontario. We appreciate being able to publish the perspective of one who expresses so well the situation of a Generation-Xer.

I am a so-called Gen-Xer. As such I am over-educated, under-employed, misdirected and misunderstood. I don't like being any of those things but I especially don't like the term itself. Generation X is a marketing term, it's a media construct developed to label all twenty-somethings as "unknowns". I prefer the term slacker. Slacker, sometimes synonymous with Gen-X, is also a media construct but what the term implies can seem more relevant to someone who grew up with the educational stimulation of such kids' shows as Sesame Street instead of its mind numbing antecedents like The Mickey Mouse Fan Club.

For those who grew up without counting or reading as part of their television diet, the term slacker may imply indifference or even laziness. To the friends of monsters however, this term carries with it an air of introspection, the profile of someone who has been given the time to think. Don't get me wrong, I'm not saying that boomers don't think, but growing up they didn't have the same amount of extended leisure time as we did. For the most part, those entering early adulthood in the 60s and 70s could expect employment, a family, and a heavy dose of middle-class values soon after graduation. That is high school graduation.

We on the other hand are usually not employed until our post-graduate thesis is complete, with little relevance in our lives for things like family, and a certain amount of animosity for anything reflective of the well-to-do middle-class. Instead we are thinkers, simply because we have been given the time to think, and along with it the time to become critical. Critical-thinking, or slack-ing, does not mean we have "figured it all out", or are somehow better than boomers, yuppies or dinks (dual income no kids). Rather, because of high rates of unemployment and the general lack of meaningful employment we have been afforded the time to question the very nature of what it means to be employed, what it means to be married, or the value of such suburban delights as the barbecue. This does not mean we are ungrateful, that we are lost, or that we have a chip on our shoulder towards the older generation. We may not want to get an "A" in civilian class but we also don't all want to move out to Seattle and do the grunge thing either. What we do want is to begin to apply what we have thought about, what we have questioned in our four years as undergraduates. We want to make our contribution to society and to be productive but first, we need jobs!

So, employers, recruiters and parents alike let's drive down the information superhighway together and pretend that you are taking us to Lucky Day Nursery School once more, only this time we'll drive because the CAR-eers of the future require someone who can learn, adapt and what is more important someone who can think. Try to keep this in mind the next time a Gen-Xer, a slacker, a thinker is on the other

side of your personnel desk. Give them a chance to tell you what they think, and if you listen very closely you may find something that at first may seem strange, like an X-ray. But thanks to X-rays consider what we have been able to see — a view into ourselves, a new perspective, and maybe even a future.

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Is the Glass Half Empty or Half Full?

SUZANNE CLANCY

We thank Suzanne Clancy and Miriam Verburg for providing their perspectives (in words and illustration) regarding Generation X.

When Paul asked me contribute some comments for this issue, I rushed to the local library and borrowed Coupland's *Generation X: Tales for an Accelerated Culture*. While I found it to be an entertaining book, I found his opus on the life and times of the current generation to be a litany of woes and frustrations,

most of which they lay at the feet of their parents' generation. My immediate reaction was: How is it possible that these Gen-Xers have the luxury of time and resources to sit around and complain about their terrible lack of opportunity and their diminished future? Just who is buying the food, clothing, airline tickets and assorted other goodies Gen-Xers seem to enjoy? Could it possibly be that same, previous, generation — the one they delight in criticising for leaving them a debt-ridden, futureless world?

While I do not disagree that Gen-Xers are facing some very challenging times, I would remind them that they are certainly not the first generation to do so. Many preceding generations have faced pestilence, war, economic depression and any number of assorted other ills and did so under far less comfortable circumstances. In fact, just this spring I was remarking to a colleague that, for the first time in my life, I wished I was 15 again. My desire to be younger was based on my new

found knowledge of computers and especially the Internet. I am anxious to live long and "surf" cyberspace, exploring all manner things I could only dream of a year ago. I was commenting that the youth of today have almost boundless opportunity to explore the world of knowledge, work, and society. They now can create new ways of doing things, start their own businesses and

influence the global village and the global economy. They have the opportunity to be the first generation to make really meaningful changes in our world, changes based on skill and knowledge, not on rhetoric and violence.

To me the glass is more than half full, it is overflowing for Gen-Xers if they choose to drink from it.

§



Generation X by Miriam Verburg

Celebrating 30ths!

SHIRLEY McNAUGHTON



Ann with her mother Miriam

First there was Ann Running's thirtieth birthday party last fall! Something set this celebration apart! There was a special excitement in the room. Now, this should not be unusual. Birthday parties are expected to be fun and a time to celebrate. At Ann's party, however, something was different! Then, this spring, my husband Bob and I attended Carolyn Henry's thirtieth birthday party. The same excitement greeted us as we entered the room. What was it that made the parties of these two women so special?

It was more than the fact that they were best friends and were influenced by each others' party arrangements. And it was more than a group of people celebrating a birthday together. I decided to explore what brought such joy and vitality to the parties with Carolyn and Ann and two very important people in their lives. Carolyn, along with her sister Glynis, and Ann with her mother Miriam joined me for an evening of reminiscing and reflecting. The following is what we think contributed to the special excitement we all felt at both parties.

What Was So Special?

First, it was a *first*! As adults, neither Ann nor Carolyn had been able to have a large birthday party before. The difficulty of having a venue with space enough to accommodate more than one person requiring a wheelchair, along with the geographical spread of family members were cited as the probable reasons. So why a decision for a party for their thirtieth? They wanted to have a "big" party to celebrate an important life milestone and they wanted to share the event with those who had made a difference in their lives. Their joy at being able to celebrate an important milestone in their life with those who meant the most to them was very moving.

And who were those people who had made a difference? Here is the second component to that special feeling that was so evident at each party. At both events, many of those attending were family members - relatives who had assumed a role with unique responsibilities, as Ann and Carolyn were growing up. The remainder of the guests were professionals who had provided many extras above and beyond their "job descriptions" and who had become friends — bringing the gift of love that friendship bestows.

From my vantage point, the parties of Ann and Carolyn provided an opportunity to mingle with people who represented the very best of their respective generations - as demonstrated by Ann and Carolyn, their parents, their siblings and their children. With regard to one of the themes of this issue, Generation X, Ann's and Carolyn's birth years were 1965 and 1966, the final birth years of Generation X (1960-1966) and the Baby Boomer Generation. The birth years of their siblings were

within the latter years of the Baby Boomer period (1947-1966) in Canada. One might expect to find, at least among a few of those present, some of the attitudes and interests associated with late Boomers - growing up in an overcrowded world and seeming to have no choice but to "look out for number 1" (Foot, 1996).

Not so, with regard to the individuals at these two parties! At each, the room had a strong component of adults in their thirties and early forties who had learned through the years, to care about the feelings and needs of others (Ann and Carolyn) and to look out for a family member (siblings). Their ability to care about the needs and feelings of others was exciting to see. Ann's and Carolyn's joy as they greeted their guests demonstrated dramatically how much their parents and siblings had done for them. And Ann and Carolyn had benefitted, as well, from the mobilizing of resources to meet the needs of those with severe speech impairments in the early seventies. The professionals who participated in these pioneering projects invested much of themselves in their work and formed strong long term partnerships with family members. When all these caring people came together to celebrate the lives of each of these AAC users, the room had to feel electrically charged!

Ann's Party

Ann's party was held at the Guild Inn in Scarborough, Ontario, in a pair of rooms that accommodated a number of round eight-person tables. There was lots of room to move and mix, and Ann was situated right in the middle, able to meet with guests one at a time and to watch and enjoy the interactions at all the tables. Her parents were there; although they

were divorced many years ago, their love for Ann has kept them partners in supporting her. Her two brothers were there with members of their new families. Friends of Ann's parents who had known her all of her life were there. They had provided much emotional support and shared lots of relaxation times with Miriam as Ann was growing up. The large rooms allowed her to have four guests in wheelchairs with no difficulty, and as well she had many mentors (teachers and therapists) who had shared in Ann's continuous efforts for learning and skill growth through the years. Ann was surrounded by warmth and caring and everyone in the room could feel it! As Ann reflected on her party, her thoughts went immediately to those who were not there — her grandmother and grandfather, her good friend, Susan Odell, and her longtime friend, Andrew Murphy, all of whom had passed away in recent years and were greatly missed by Ann. During an occasion like her thirtieth birthday, she felt they were with her as well, but "in her head".

Carolyn's Party

Carolyn's party was held in a hospitality suite at a Radisson Hotel in North York. The size was just right to accommodate both Carolyn's and Ann's wheelchairs, Carolyn's parents, her sister and two of her three brothers and their children, her uncle and his family and a few friends from her school days. It was her sister, Glynis who helped Carolyn plan and host the party. Ever since Carolyn moved to Toronto from Cornwall, in 1982, she and Glynis have had a close relationship. It was fun to see the young nieces and nephews gathering around Carolyn to see her new Lightwriter. I



Carolyn and Glynis

felt the same feeling of warmth and caring throughout the room as Carolyn greeted her guests and enjoyed her special event. There's something about the guest of honour with sparkling eyes and a happy smile, sitting in a wheelchair surrounded by friends and balloons, and dressed in her party-best that gives the occasion special meaning. This is how it was for both Ann's and Carolyn's celebrations.

Reflecting on the Parties

In talking about my observations with Ann, Carolyn, Miriam and Glynis afterward, I asked them what they felt had contributed to the special atmosphere at the party and how growing up with an AAC user affects families. This is how they responded: It makes the family members closer and the family unit stronger. Brothers are very protective but still tease! Regarding communication, all members understand - even the dog! As adults, siblings are sensitive to hiring practices and support the hiring of persons with disabilities; they have a greater awareness of needs of others. All family members are helping the next

generation in the siblings' new families to appreciate the needs and accomplishments of AAC users.

No wonder I felt a special something in the party rooms! I am fortunate to frequently interact with caring professionals, AAC users and their parents who continuously stretch themselves to meet the needs of others. On the occasions of Ann's and Carolyn's birthday parties, however, I experienced that extra of having AAC users, parents and professionals together for a special event and reinforced by their extended families. Truly memorable days!

If you are lucky enough to be invited to the birthday party of an AAC friend, do your utmost to attend. You will meet the nicest people!

Foot, D. (1996). *Boom, Bust & Echo*. Toronto: Macfarlane Walter & Ross.

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Ann and Carolyn

ComTog Online

ROBERT HAAF



Rob Haaf

Well, the time has finally arrived! By the time you read this, the first “draft” of **Communicating Together’s** site on the World Wide Web will be up and running. The site is designed to be as “access-friendly” as possible, so while the pages contain many photos and graphics, text-based versions of each page are immediately available to accommodate those with visual impairments who may use screen reader software. At the site, you can see and read about the editors and contributors, and even email those of us who are “wired”, to make comments or suggestions about the magazine or a specific article.

Like many Web sites, **ComTog’s** site will help to increase exposure to the magazine for a worldwide audience. More than that, the site allows anyone to subscribe to the magazine online, and to download the entire contents of the most recent issue (complete with photographs and any other media) for reading on-screen or for printing out. It is hoped that in the near future, back issues of the magazine will also be available to subscribers for downloading. One significant

advantage of an electronic magazine is that it can allow individuals with disabilities, many of whom already use adaptive technology to access computers, to have more independent access to material such as **ComTog**.

The electronic magazine is offered in a text-only format (to accommodate screen readers for the visually impaired) and in Portable Document Format (PDF), an electronic publishing standard that preserves the magazine format (with text, graphics and other media) and is readable on any computer platform. More details about PDF, the free PDF reader software and details on downloading **ComTog** are available on the “**ComTog Online**” page at the Web site. It is important to note here, though, that the PDF reader program can currently be accessed using any adaptive equipment that allows mouse emulation, and efforts are currently underway to provide software setups specifically for the PDF Reader, for several widely used computer access solutions (e.g., Ke:nx, IntelliKeys, ClickIt). When this software is completed, it will be available for downloading at the **ComTog** Web site.

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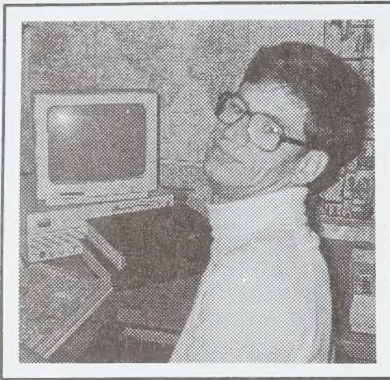
Ultimately, the site is intended to both increase interest and exposure to the magazine and to accommodate **ComTog** subscribers. Therefore, a table of contents and sample articles from a recent issue will be available at the site, to give “surfers” a better idea of what **ComTog** is all about. The complete electronic magazine, however, will be protected, so that only those with a password (i.e., subscribers) can open and read the file. Having said this, the September and December 1996 issues will not be password-protected, so anyone can download them and try out the PDF document for themselves.

While you’re exploring the site, keep in mind that it will be undergoing significant development and expansion. We hope to offer links to many other sites devoted to AAC and disability issues, and to expand the site to include information about all Sharing to Learn publications. If you have suggestions, links to interesting sites or any comments, please drop us an email from the site. Have fun, and let us know what you think!

§

The Impact of Generation X upon the AAC Community

PAUL MARSHALL



Paul Marshall

What impact has Generation X made upon handicapped people and especially on the augmentative and alternative communication communities? We know a lot about the force that this event had, and has, upon the mainstream society. But it is my feeling we possibly know very little about the bearing it has had on the handicapped society. Other than my own thoughts and reflections, I have no additional data or facts on what I am going to share with you. I was born in 1963, which makes me a Gen-Xer. In the 60's the western world was just at the stage where the hope of integrating anybody with a handicap was just starting to occur. It was a time when our society was changing from having a closed view on any form of integration to a more open view of having "disabilities" being seen in the community.

As I was growing up, when I was out shopping or just out with my family, I always got those stares (you know as if I was more handsome than my two older brothers!). People looked at me as the "poor boy" who might not have a very good lifestyle of his own. More than likely, they just couldn't comprehend the effect that would take place in the late 60's to the early 70's. In Canada the government couldn't keep open the large institutions that housed many disabled people. This had a major effect in getting our society's eyes pulled wide open to realize that they had a responsibility to care and start integrating the disabled individual. It is my own feeling that because of the deinstitutionalization and a very high likelihood of the birth of babies who had special needs in the Generation X era that we saw better services developed.

These two events taking place radically changed how our society viewed anyone with a disability. There was a great movement to get services in place that provided people with special needs with the access to the education systems and countless other resources in the community. Today, we are providing normal schooling to people with disabilities, making the distance between being segregated and integrated much narrower. In the last 30 or 40 years we have gone from total segregation to total mainstreaming. Is this good? Are we creating false hope and expectations in the education systems, or are we just providing the disabled person with the same options as the "normal" Gen-Xers. If our society is mandating equal education to our

population — which they are in Canada — we had better be ready to provide housing, access, and the equal opportunities and responsibilities that come out of being mainstreamed in the education system.

There is no doubt in the late 80's and the early 90's we began to see the nonspeaking individual really starting to integrate in the everyday life. As we face funding cuts here in Ontario and I am sure it is happening worldwide, we are going back to seeing less integration generally. When we think of the nonspeaking society, we must realize that when it comes to having visions of what will be needed ten years down the road, and to having advocating skills within its members, these are very hard to come by. We don't have a volume of "voices" to lobby in government to keep services in place. Others have, and they are lobbying on our behalf, but the people and their families who could benefit from these services, are so busy trying to meet their own daily needs that they don't have the options of developing visions for long term planning and lobbying for these badly needed services.

We badly need visionaries from the general group of Generation X to come and join with us and be our voices. We need individuals who are willing to "jump off the bridge" and are willing to develop their "wings" as they fall. Isn't this an ageless creed of being alive? We seem sometimes to be moving away from teaching our future generations to be compassionate and caring people. It's time to reflect and step out and start to develop "wings" for others! §

Family and Parenting Issues

VICTOR VALENTIC



Victor and his family

We are pleased to be able to include Victor's article in this issue. We welcome giving our readers this opportunity to learn from an AAC user and his family.

This survey was prepared by an augmentative communication user. It was completed by the parents of this AAC communicator. I have prepared questions which my parents have answered. Keep in mind this is my family and just as I am an individual, they are too.

1. What were the difficulties you encountered in raising a disabled person through the years?

A. The major difficulty was that as parents we were aware that we were going to have to use alternative ways for you to do certain things. The difficulty was not with you but with educating the world around you to step aside and allow you to discover and try things on your own.

2. How did you raise me?

A. You were raised as a child first, and one who was going to grow up in our family, and view the outside world according to our interpretation. The fact that you had a disability only entered into deciding how we could attempt to accomplish the every day ordinary life experiences that we felt were essential in the life of a child we were raising.

3. Were you afraid to raise me? Why or why not?

A. We were not afraid to raise you, for no matter what aspect of your life we were dealing with we always felt that the Lord would guide us and show us the way. As your mother I feel I have been privileged to have witnessed a miracle. As parents we are so thankful to have had the opportunity to share our lives with you as our son, and we cannot ever take this lightly for our past experience has enriched us.

4. Viktor and Lois, are you saying that you were happy with my difficulties?

A. It was not a question of being happy with your difficulties. It was that they were a part of you, and who better to help you improve, overcome or accept them than us. As a result of your illness we were well aware that if you did survive there would be things which we would have to accept, and being realistic people we felt that we would put our time and energy into working with you to help you improve to whatever level was possible.

5. How did you explain my disability to your family?

A. Explaining your disability to our families was done through a process. The outlook for you from a medical standpoint was not terribly promising; however, as parents we felt that you had survived a very severe illness. We must try and get you as healthy as possible, and as your health improved that was one less area to be concerned about. We were then ready to evaluate what parts of you were changed and get on with re-teaching what was possible and regaining and developing new skills to replace what was lost. Because so much was happening, these were the things we chose to tell our families, and of course they were a positive influence because they too were overjoyed that your life was going on. You laughed, played, enjoyed interacting with them — no matter that you communicated with them by pointing at symbols so they could learn what you had to say to them.

6. Over the years your family and your son came closer together. Can you explain what was the moment that Victor realized the role he played in your family?

A. I think that Victor has always known the role he plays in our family. He is our son. It was our intention to raise him to become an independent person, prepared to look after himself and seek a role in life which would give him purpose and share the gifts which he has been given.

7. *Why is it important to you that Victor complete and graduate from Mohawk College in Hamilton, Ontario, Canada?*

A. It is important to us as parents because this will be the end of one step in his education. We have always felt that he would accomplish this without too much difficulty, the next stage where he will actually use the knowledge and skills he has acquired from his courses in a job or higher education will be another new beginning for us all.

8. *Why do you think he feels any goal in the world can be reached?*

A. As I look back over his life, there have been many goals. As a young child he told me he would attend a certain high school. At that time he was walking with the help of metal leg braces and heavy orthopaedic shoes, barely able to walk a short distance without losing his balance, communicating on a mini version of his Bliss board which was attached to his waist. At that time, I thought how am I ever going to be able to tell him that he would not be allowed to do this. For at that time, individuals such as him were not attempting to enter regular classes at that high school or to my knowledge any of the other ones. This was his dream, and so it was to remain, as we all worked very hard to ensure that he would be ready to move to that stage when the time came. That dream became a reality not too many years later. We as a family sat in the auditorium, on a sweltering June afternoon, as he walked on stage to receive his high school diploma in that very high school.

9. *Are you telling me that his goals are no problem for him?*

A. I don't think Victor sets goals for himself keeping in mind that he may encounter specific problems because of his disability. He knows what he wants and simply proceeds towards the goal of the moment, solving and overcoming obstacles as they present themselves. At this stage he manages most of the decisions on his own. He sometimes asks our opinions about some of his "logical decisions" as he calls them. He listens to what we have to say but he always makes up his own mind. He likes to handle situations on his own, but because we have lived a lot longer than him he sometimes wants another perspective. We give it to him as honestly as we can and allow him the space to make his own judgements and mistakes as all young people must do in life.

10. *Does he like to have fun with you?*

A. Yes, he is full of fun, he has been blessed with an uncanny way to bring humour to almost any situation in life that would bring tears of exasperation to most. He never fails to miss an opportunity to look at the lighter side of life. He likes to play jokes on me. Those mornings when I am in a hurry to help him put the finishing touches on his hair, and I enter his bathroom — to my surprise he is nowhere in sight. Off I go into his room only to return to the bathroom and he will peek out from behind the shower curtain to jump out at me and startle me. I don't know who is more startled, him or me. Somehow this gets me back on track. Life is not all seriousness to him.

11. *In the end can you wrap up and name a point in his life that he underwent a dramatic change?*

A. I think the point when we noticed a dramatic change was once Victor decided on a speech device that was a quality of speech which he felt equalled his mind. He used it not only to make communicating with us easier and much more in-depth, but he allowed others the opportunity to know him, and listen to what he had to say about things. Thus I am sure for many it probably was a first for them to discover that he had many things to contribute to conversations they were now able to have with him. We as parents have always known the real Victor, not just assuming and taking things for granted. But for outsiders who did not have the tools or the time to discover just what he was all about it has opened up many doors for him to continue experiencing life.

To be a member of a family it is important that each member communicates with each other. Oh brother, we are communicators in my family! My father, as a Yugo-Canadian immigrant, my mother, as Mrs. Canadian English, my sister, as Miss know-it-all, and me, as an augmentative and alternative communication user with a Liberator!

My first recollection of my father was hearing his voice and his pronunciation of the words, which was different from that of the other people that I heard talking to me. When I heard my father speaking in a different language to his cousins, I thought "I hope my parents won't be expecting me to speak this language!" My first memory of my mother was when she was talking to me. She was different than my father, I thought,

"Thank God! She speaks real English, not Yugo-Canadian and I will have a really, really good chance to learn English!"

Now that I am writing and speaking English I remember all this. I was raised with a younger sister. She was five years younger than me. She developed her problem-solving abilities very early in life. She could tie shoe laces earlier than most kids. She learned on mine! I can recall how she solved my broken zipper dilemma when we were both in high school. After my parents left for work, I broke my pants zipper. She helped me out with her solution which was to use straight pins to close up the opening. Somehow I knew that wasn't right! Eventually I convinced her to try something else. She came up with safety pins. I still wasn't convinced this was the best way to go. What if I needed to go to the washroom while I was at school?

I sure couldn't undo pins, never mind putting the pins back in again. I didn't want to hurt her feelings, so I just went along with it. Once she left for school I phoned my mother. She listened and suggested that I remove these pants and put on another pair. This was all possible, but since I was unable to tie up my shoes, and my sister wasn't available any longer to do them for me, I would have to go to school with untied shoes. I finally changed and off I went to school. This was the first time I was late for high school. Once I got there I asked a teacher to tie up my shoes for me. From this experience I learned that even though others might make suggestions to me on how to overcome a problem, I must rely on myself to come to a solution which I felt comfortable with.

Years later, my cousin and I grew closer together. One time we had a

five-hour conversation discussing the loss of her little brother to cancer. The extended family is so important! The unit of a family must be tight. However, I know some families are not tight. My reason for telling you this is that you must talk to each of the family members. Talking out problems ensures a strong family unit.

In conclusion, in the short time I have lived in my family I know that our family has been strengthened by the amount of communication we have with each other. Each of us has our own particular way of doing so, but we all get our points across!

My email address, to communicate with me or my family is: Vic Valentic
<loren@interlynx.net>

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FAMILIES AND PARENTING IN LATVIA

ALDA STEPRANS



Sigita and Evija

One of the benefits of travelling is that of meeting new and interesting people and while I was in Latvia I had the fortune to encounter the Lapins family, shown in the photograph. Sigita, the mother is on the left and her beautiful 15 year old daughter, Evija is beside her. What the picture does not show is that Evija, as a result of brittle diabetes, also has seizures, mostly during the night but occasionally during the day. Sigita and Evija tell a story that is very suitable for this issue, for it tells about how parents in Latvia have to lobby and advocate to get the very basics for their handicapped children, even for children who in our society would not be considered handicapped. It is interesting how cultures define handicap and disability differently.

I asked Sigita what life had been like for handicapped people in Latvia during the years of communism. Sigita answered that in the past there

were, officially, no handicapped children. People were not looked upon as individuals in that society. There was no acknowledgment that some children had special needs, so there was no need for schools for them. Some children, who could not attend school regularly, were home-schooled. The teacher arrived once or twice a week and left lessons, but there was no active teaching done. In reality, the parents taught these children, who were basically hidden away at home. Parents were told the child's diagnosis, but other than that, usually received no information about how to help the child, what to look out for, how to prevent complications.

This lack of information and support as well as the considerable shame in having a child who was not "normal" resulted in many families giving up their handicapped children to orphanages. The many orphanages that exist in Latvia are still primarily full of handicapped children, who have parents, but whose parents don't care for them. Over the last five years, since communism has ended, the orphanages have become more like boarding schools, where the children live together and are cared for physically, but are also taught and given the therapies they need.

The few I visited proved to have very caring staff. Most of the children were actively learning, or doing things, in spite of their handicaps, severe space limitations and a lack of cause and effect toys. A psychology student that I met expressed her concern about the effect lack of individual parenting will have on these children. It is interesting to note that psychology is an entirely new profession in this country. When Latvia gained its independ-

ence from the Soviet Union, the parents of handicapped children all over Latvia, including Sigita, banded together and formed the organization "Rupju berns" to help each other in their quest of finding out how to help their children. The name of this organization, as I mentioned in a previous article, means "the child who requires care, or worrying over".

Prices of the little medication and clothing and food available in stores rose phenomenally, while unemployment grew. Parents of handicapped children needed help. They also wanted to have education available for their children. "Rupju berns" did receive considerable assistance from many countries, in terms of care packages of medication, food, used wheelchairs (which were especially valuable in giving these people some freedom), as well as trips abroad, which permitted them to see how handicapped people live elsewhere. This helped them not only to survive, but to understand that their children could learn and find their place in the real world. They used their contacts in the local government to communicate with people in democratic countries and acquire space to start schools. But all levels of government in Latvia are very poor and their help has been minimal.

Evija had tried to attend a local school, but encountered various obstacles. To begin with, teachers were not very understanding when she felt ill or missed class time. Expectations for students are much higher in Latvia than in Canada. (My children were at least two years behind their classmates in math. All children start learning biology at a fairly sophisticated level in grade 5, physics in grade 7 and chemistry in grade 8.) Evija could not master

many of these subjects, because the seizures have affected her memory. Furthermore, there was also no place for her to store her insulin and no place to inject it when she needed it. The washrooms were, and still are, very unsanitary. There was a real stigma to having an injection in the open. Such people were labelled and treated as drug addicts.

Evija spent a few years learning at home and then, in 1991, Sigita helped to form a new school, the "Rehabilitation School for Invalid Children" in Riga, Latvia's capital. Evija has been very happy since she started to attend this school and is even sad over the holidays because she misses her friends and teachers so much. The teachers are like real friends. The students help each other and spend a lot of their social time together. Evija added that they do not feel handicapped when they are together. Evija also attends the "Diabetic Association" meetings and has been to "Diabetic Camp", which are both new notions here. Evija has found them very helpful. She gets valuable information from the staff, but more importantly, from the other diabetic children. She often finds herself giving advice and Sigita is frequently phoned by other parents who need urgent help.

Integration is a buzz word in Riga as well, but has not worked out very well for most of the children who have tried it. For one thing, buildings are not wheelchair accessible. Evija is not wheelchair dependent, but some of her classmates are and at the Rehabilitation School, a man has been hired to physically carry the wheelchairs and their occupants up and down the stairs. In this building, the school is all on the first floor level, so the number of stairs is minimal, but Sigita told me of one wheelchair user who attends a

regular school and has many of her classes on the fourth floor. This girl can walk a little, but requires help up and down stairs. Her mother has hired someone to help her before and after school, but between classes it's a struggle, and neither the teachers nor the other students have ever offered to even bring her up some lunch. It will take time for the attitudes of teachers and students to change, and even for this girl to learn how to ask for help. "

Rupju berns" has changed its focus over the years as well. It has now divided into interest groups and bands together to effect changes on a government level. Although Sigita knows some 22 families with handicapped children in her immediate area and helps to find assistance for them when they need it, she does not know the true number of handicapped children in her region. In some cases this is due to the shame felt by some families having abnormal children. In other cases, these children are born into families where there is a problem with alcohol abuse, a legacy of the communist era whose consequences are felt in all aspects of life in Latvia. Poor families do not register their children with the government, to avoid paying taxes on heating, water and other utilities which are levied according to the number of people registered in each apartment. The government subsidies per child which families receive are much lower than these taxes.

Five of the physically handicapped students at the rehab school, including Evija, graduate from grade 9 this year. Grade 9 graduation is a special event for most Latvian children, as they head off to high school, but it has a sad overtone in this school because after they graduate these teenagers will have no

place to go, no place for them to spend their days together. Once again, some of the parents, especially Sigita, are lobbying to start a centre or school for them. The government cannot afford to sponsor such a project, but I urged Evija and her friends to try to find places to meet even though it's hard because so many of them use wheelchairs. But, where there's a will, there may be a way. It's certainly worth the encouragement and the effort!

What does Evija's future hold for her? I am uncertain about this, but I am sure that it holds much more for her, than for the majority of handicapped children here, whose parents are not advocating for their right to learn, for their right to a better future.

The Rehabilitation School

Through Evija and Sigita, I had the wonderful opportunity to visit the "rehabilitation" school for physically and handicapped children. The children there seemed very happy and their bright faces, shy smiles, independent movements around the school and ability to help each other impressed me a great deal. This school opened its doors five years ago, due to plain old need and parental lobbying. There are 8 classes in the school. Half are for Russian speaking children, half for the Latvian. Six classes are for mentally handicapped children, two for the physically handicapped. In the Latvian half of the school there are about twenty mentally handicapped children and four who are physically handicapped.

The school has about one teacher per four-five students as well as two speech therapists, an art teacher, a music instructor, and a physician. The children also get to mold clay. A potter has installed a kiln in the

basement of the school and works with the children on a regular basis. The art work, in general, is exceptional! The teachers said that initially they had no real knowledge of how or what to teach these children. They just try to help each child as much as possible. I assured them that they're off to a good start, just by noting that each child is unique and has special attributes, strengths and talents. Education is very important to Latvian families, and although some allowances are made, the physically handicapped children in the school follow the same curriculum as the regular students. However, there is no meaningful interaction between the local school's students and those of the rehab school. Part of the reason may be that this local school is for Russian speaking students and half of the students in the rehab school are Latvian speaking. Still, the students at the rehab school feel much surer about themselves than they did initially and often move around the neighbourhood independently now. The teachers say that although at first they were all a little self-conscious when they went out together, now they feel surprised if they find someone staring at them.

By the way, the children at this school are also learning English. They don't have computers and therefore can't communicate via e-mail, but they would be wonderful pen pals for anybody who would like to correspond via plain old mail. These children asked a lot of good and interesting questions about handicapped children and teenagers in Canada and elsewhere. I did my best to answer them, but you probably have more accurate and helpful information than I do. If you are interested in being a pen-pal, forward your address and some information about your age and hobbies to me at 237 Fairview Avenue, Toronto, Ontario, M6P 3A6 or via e-mail at steprans@mathstat.yorku.ca

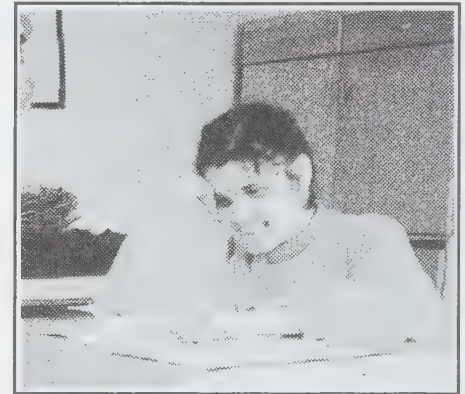
and I'll be happy to pass it on to the school in Latvia. This would not only be a boost to these wonderful students' morales, but would really help improve their English skills as well.

The children with mental handicaps are taught by chance. There are no schools, no regular seminars to help the teachers understand how to teach these children. Of course, the teachers feel that they could do a lot more if they had more knowledge and materials. They feel very insecure about their skills. Toys are available in the classrooms, but the ones I saw were not especially creative. Of course, the teachers feel that were the Latvian government and their school richer, all these problems would be solved. Naturally, it would be wonderful to have computers, video cameras and television sets in every classroom, but I assured them that there is a lot they could be doing that is not so costly.

I remember many marvellous teachers my own children have had and the interesting ways the therapists teach the residents in my hospital. I know that they also lack the funding they deserve. How have they made exercising and learning fun? I remember play dough (that can also easily be made at home), water tables, wooden blocks, letter games and will pass on the ideas that have come to my mind. However, I'm also certain that you, the readers of **Communicating Together**, may remember many of the things that helped you, your students, or your loved ones learn something more easily or in a more exciting way. What struck just the right chord for you? I would love to know what helped you learn to read, write, understand a concept in math or science in some special way. What fond memories do you have of teaching or learning? If you could

pass your ideas on to me, I would certainly send that information on to the teachers of this school, who are requesting this information.

It is surprising, that there are so few students in the school. One of the teachers told me that to find new pupils the teachers literally have to go door to door. If they hear of a family with a handicapped child they visit that family, try to establish friendly meaningful contact and with time, try to convince the parents to bring the child to school. However, there is a great reluctance to do so. Many parents don't see the sense of educating these children. They feel that they will never be able to do anything with an education.



Zanete

A good case against this point of view can be made by considering Zanete, (Jeanette), the bright little 14 year old girl, you see in the photo here, learning how to spell. Her speech muscles were paralyzed from birth, but she understands everything. How wonderful it will be for her to be able to truly express herself for she now is learning to read and write! Her parents were very reluctant to let her go to school, but since she started attending this past September she has simply blossomed. I watched her skip down the hall, giggle through a

music class, start putting letters together to read, take another little child's hand to help him out. It's hard to reassure many parents in Latvia that the environment of a school can be a caring one. History has not been kind to the handicapped here. These children have been looked upon as sick, invalid and as problems. I was

told that some parents just can't be bothered getting the child dressed and fed to go to school, even though the school has a bus that picks the children up. Even children like Evija, who have no visible handicap, are penalized for having chronic illnesses. I was very impressed by the efforts of the people

in this school. The atmosphere is a caring, loving one, full of expectations, respect, and acknowledgment. The children are involved and happy and able to speak up for themselves. It will be interesting for me to keep in touch with them, try to send them information and ideas and see what the future holds for them.

The Barriers We Face: Ignorance and Impatience

EVELYN MOSELEY



Evelyn Moseley

Last fall, Peg Johnson of Richfield, Minnesota, had the opportunity to attend the 1995 National Communication Conference in Melbourne, Australia. She had been invited to give the opening address and was thrilled to be a part of such an event. Most of the speakers at the conference were, like her, living with some form of communication disability. Some had been disabled from birth, others had an acquired disability. One speaker in particular, Evelyn Moseley, impressed Peg greatly. We are very pleased that Evelyn Moseley agreed to us printing the following extended excerpt from her presentation and we thank Peg Johnson for sending Evelyn's presentation to us.

More and more emphasis is placed on communication in these modern times. It is an essential part of living in the twentieth century. Now is the age of mobile phones, faxes, computers... and technology is moving forward all the time. Communication is so much a part of living that too many people take it for granted. It's sad that technology is so far advanced and yet some people can be so backward in attitude. Even though technology can produce communication aids for people who need them, most of the community still treats you as a lesser person if you can't speak or can't communicate. People with communication difficulties face battles every day of their lives because they have such hardship getting their message across to other people. These battles are invisible barriers implemented by society. They stem from people's attitudes which in turn stem from ignorance.

I don't think anyone can fully understand what it means to be unable to communicate until they find themselves in that position. Only then does one understand the limitations that are placed on people with communication difficulties. Before my illness I could walk and talk. The only communication barrier that existed for me was my shyness.

In 1980, when I was 23, I went on a holiday to Bali and Java and contracted viral encephalitis. It left me completely paralyzed and with-

out speech. I was dependent on others physically and for communication. For six weeks I could only communicate with my eyes, blinking yes or no in answer to questions. Then an occupational therapist drew up a communication board (alphabet board) for me. This worked well with people who knew me, although it was slow. Meeting new people, however, was a frustrating experience. Because I couldn't verbally talk, they never gave it a thought that I might use an alternative form of communication. Even when they became aware of the communication board, they would direct their conversation to the people with me, not to me personally, and they avoided eye contact.

This was when the impact of the communication barrier really hit me. I had become invisible. It was the same situation when I started using the Canon Communicator as a communication aid. It works much like a typewriter, only smaller and more compact. At first I depended on other people to hold my wrist over the Communicator to tap the letters, and this was frustrating because some people could not do it very well.

Communicating in this way is very slow. I hardly ever joined in conversations because I was too slow. By the time I used my Communicator the topic had moved on to other things. It was also disempowering having to wait until

people had time to help me communicate. But even then, I had to be careful with what I said. If I was fighting with whoever was looking after me or if I didn't get along with them I was completely at their mercy. That situation was very unpleasant. I didn't like anyone having the power of withholding my voice. There was also the issue of privacy and confidentiality. I regarded most of what I said as private and I always had my printouts discarded after a conversation. Sometimes, however, other people would find them and read them. Time was always a problem too, having the time with nursing staff or visitors to spell out what I wanted to say. I couldn't say a single word without someone's help and sometimes no one was available.

It was wonderful when the day arrived that I could communicate independently. After many years and a lot of physiotherapy, my wrist became stronger and I could use the Canon without having to depend on someone else. The Canon Communicator was strapped to my leg so it was within easy reach of my hand and I could use it whenever I wanted, with some limitations like spasms, or the weather freezing my hand. My communication had been restricted for so long, but now I was free to say what I liked, when I liked.

In the last few years I have regained my speech. My voice is very soft, just like a whisper. I have trouble with certain sounds and often spell out letters and words. I still rely on my Canon Communicator as well. Now I can use a computer too, so I can write as a form of communication. It has boosted my confidence a lot. Being able to independently communicate has put the focus more on me. People have no choice but to look at and address me.

Looking back, I can see that the effects of communication barriers to

me were very severe. The minute I lost my speech I became trapped in a world of my own, isolated from everyone and everything. My thoughts became uncontrollable, because I couldn't express them. This communication barrier shattered my confidence and took away my ability to make decisions about my life. I seemed to lose a part of myself. My family and friends continued to treat me as they always had, but other people wouldn't look at me, let alone talk to me. It is so incredible that the instant you are not able to verbally communicate, people tend to ignore you and talk over the top of your head.

One big barrier we face is the lack of contact between people with a communication impairment, and the rest of society. Since the International Year of the Disabled in 1981, public awareness has been raised about issues of disability. With the introduction of the Disability Discrimination Act (Australia), more people are becoming aware of problems and barriers of the disabled. But the barrier created by lack of communication still needs to be more fully addressed.

Most people have never conversed with a person who has communication difficulties and are not aware of what it involves. It requires a great deal of patience, a lot of understanding, and, of course, time. Good listening skills are a must, as well as a good attitude. There are always some who won't even try. These are people with narrow minds who believe if you can't talk, you can't think, or that you are deaf. They are often short on patience and understanding.

Time is a commodity that is not always available in this busy life. It is one barrier that will always be present and nothing will ever remedy that factor. People with communica-

tion difficulties need time to express themselves whether they use a communication aid or not. The person they are conversing with also needs time available so they can be attentive. People sometimes speak the truth when they say they don't have time, but sometimes it is just an excuse used to avoid getting involved.

Probably the biggest barrier we face is that people have a fear of what they don't understand and have trouble accepting people who are "different". People will automatically put up their guard if they meet someone new and they don't know how to converse with them. Society commands certain standards and having communication difficulties does not fall in with these.

Curiosity is part of human nature. People might not mean to be rude when they stare, ignore, yell, or treat us like we are stupid. Ignorance exists because people don't know any better. It is unfair to categorize anyone. We are all individuals in our own right. We all have rights and no one should be dismissed just because they have difficulty communicating. We should not be treated like second class citizens.

What we need to do is develop strategies to deal with public ignorance, to tell our stories, to become more visible in the public eye, and to work to bridge the gaps that are created by communication barriers. This conference is the first step in this direction.

If you would like to know more about the 1995 National Communication Conference held in Melbourne, or if you would like to get in touch with Evelyn Moseley, contact CAUS (Communication Aid User Society), 11 Station Street Malvern 3144, P.O. Box 43, Ormond 3204, Australia.

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From Dualism to Relationships

GEB VERBURG



Geb Verburg

I have asked myself whether I would want to live in today's world as a child or teenager. For some ten years the appeal of (re)living as a teenager has been discouragingly low because of the Gen-X feeling. More than once I have wondered about the wisdom of having children in a world where we are overpopulating, abusing, polluting, destroying, and overburdening this enormously beautiful planet we live on. And even though our bad habits are still continuing and we are still killing several species of animals and plants a day, I am beginning to be a bit more optimistic because I see evidence that we might be able to learn to live within our ecological (and perhaps economical) means.

This article will depict Generation X as a marker species of our society. You know, one of those animal types that signals the health or ill-health of an environmental niche. I believe that Gen-X, although not overall an enviable "species", nevertheless marks a change in world-view from the old Cartesian dualistic and materialistic attitude in which people believe themselves to be 'lords and possessors [despoilers]

of nature', to a way of thinking that values the earth as an equal partner in what might yet become a sustainable relationship.

I choose Gen-X as the turning point because it is the first generation that without a war or depression is (perhaps per-force) anti-, non- or less- materialistic, small scale, self- and other-centred, a generation that has elevated re-using to an art form. There are other properties of Gen-X that I will get back to later.

Eco-Design

Karrie Jacobs, in an article called "In Search of the Green Machine" in the March/April 1995 issue of *Industrial Design* describes the rise of the "eco-design" movement. Eco-design strives for complete recyclability of all that is manufactured or produced by society, using no more than the energy produced by the sun. Business, surprisingly is beginning to ask for such an approach perhaps as a result of a combination of consumer demand, new environmental guidelines and laws, and sometimes for purely economical reasons. This approach is also being pursued in Europe as indicated by a goal, defined by the German chemist Michael Braungart, which is to move towards the use of only two categories of goods. Category One are the disposables, things that we use and dispose of and that are edible by some kind of living organism. The second category of goods, according to Karrie Jacobs, "are products or services that include everything from automobiles to packaging. The idea here is that the purchaser merely licenses its use. When the package is empty or the car kaput, the manufacturer

must take it back and reuse or recycle the pieces". Pursued to the letter this approach would result in full recycling of all products. This cyclical approach would mean a very dramatic change from current linear recycling philosophies where disposal occurs at the end of a product's lifetime instead of being part of the product's lifecycles. Braungart identifies a third category of goods consisting of toxins and elements that do not fit into a cycle. Their use would be phased out and forbidden. This scheme might sound a bit dreamy but this complete commitment to a cyclical sustainability is exactly what we need in order to get rid of the skidmarks on our planet.

Relationships

In earlier columns I have complained about the dualism, self~other, subject~object, good~evil, person~world, etc. that permeates our society, language and thought and have expressed the hope or desire to go beyond this simple-minded and inherently antagonistic method of interacting. Cartesian dualism, both the self~world and self~other varieties, developed at the same time that Western civilization began to seriously despoil and abuse the earth's physical resources. This coincidence is not accidental because dualism objectifies the earth and its resources and in doing so provides a justification for robbing and abusing Earth.

How does this relate to Gen-X? I believe that western civilization is beginning to develop a new attitude towards the earth and earth's resources. I strongly believe that parallel to this new attitude, new interpersonal philosophies and

Looking Back

SHIRLEY McNAUGHTON



Shirley McNaughton

*The December issue of **Communicating Together** will have as its theme "The Experiences of Cohort Groups" and will look at the different influences through the decades that are experienced by persons who lack functional speech. We will feature articles by those who have served several cohort groups during their involvement in AAC. We will be taking time for reflection and consideration of what has gone before. The following excerpt from a paper I prepared for the ISAAC-UK Newsletter in 1989 is included in this issue — in anticipation of our looking back over the decades in December and as an interesting complement to the book review that follows.*

My work with ISAAC, with Blissymbolics and with teachers who provide educational support to students using all forms of augmentative communication, has opened a world of learning to me. I delight in exchanging ideas relating to the many facets of our field. My focus has been upon augmentative communication for children,

but as 'my children' have grown up, I have tried my best to relate to the new challenges they face.

In 1971, when we first began teaching Blissymbols to children who were nonspeaking, we were rebelling against the limited communication offered by the picture boards of the day (constructed with pictures collected from magazines and catalogues) and we resisted the lengthy and, considered by us, inappropriate process involved in teaching children to read prior to their development of a strong face-to-face communication system. We recognized the valuable language and cognitive learning that young speaking children derive from talking and interacting with people and we sought a rich complement or substitute to speech that could serve as a foundation for literacy. Blissymbolics provided a medium that has offered endless learning both for those who use it and those who teach it.

Our technology in Ontario consisted of the typewriter, although we had read about the use of the Possum in England. Prototypes designed by sensitive technicians gave us early rudimentary devices through which we could demonstrate the capabilities of the young nonspeaking children we served. We had to demonstrate that they could think and that they were capable of operating devices to communicate. We had to show that augmentative communication was possible and that it did not inhibit the development of speech. To-day augmentative communication specialists can focus upon assessment, selection, accessing and training and they have a multitude of commercially available graphic sets and systems and different types of technology from which to select. In the

practices will also emerge. From what I have seen of Gen-Xers in my environment I think this is happening. I have had the pleasure of seeing young people develop new relationships and new forms of relating. You can all see that stereotypical male and female roles are beginning to disintegrate, and that slowly, ever so slowly, the male dominated society is giving way to a more egalitarian gender distribution in power structures.

The people who make up Generation X and who, in spite of the daunting and depressive odds, the macjobs, the impossibly overused tractorpath of life, have the courage to go out there, do their jobs and have the energy to begin to build relationships that are as mellow as the best of the sixties, and more original — even though they do not see it yet. These relationships are also real and robust. The novelty that I see in the relationship of the teenagers of today are the relative lack of competitiveness and materialism, the reduction of the macho-ism, and the equivalent diminishing of the barbie-ishness of young women. Generation X is the first generation that is learning to live in a sustainable way in a world with known limited resources. No one says that it is fun or easy. In that respect Generation X has things in common with people with disabilities, who irrespective of the generation they happen to be in, have a life that knows more obstacles and more limits than any Gen-Xer. To be both Gen-X and non-speaking is possibly a double challenge and my hat is off to Nola and all like her who have met futurelessness, looked it in the face and said: "I'm going to make a future anyway!" I think with Paul Marshall that this is the right choice and that things look less bleak than the mystique of Gen-X will make us believe. Good Luck and God Bless you! §

seventies, we had to focus upon the individual's right to communicate.

Professionals in our field now know much more about facilitating interaction. Researchers are beginning to give us bits of information relating to many different aspects of augmentative communication; developers are providing us with exciting technical capabilities; case studies are beginning to be published and manufacturers are providing us with reliable devices. Our theoretical knowledge as a field, however, is still very limited and we must rely heavily upon the specialized skills and personal experience of individual professionals. Thankfully, augmentative communicators are growing up and telling us what we did right and what we did wrong! It is most interesting to listen and learn from them, while at the same time recognizing that they have their biases derived from their experience and training, just as do the different disciplines.

We have been very busy as a field, developing service delivery models from which we can apply and investigate many types of augmentative communication. We have made tremendous gains in the past two decades. Yet, as I observe children being introduced to augmentative communication systems, I see many major gaps in the support we provide - gaps which I believe can only be addressed through a broadening of our field's knowledge and participant base. To date, we have benefited primarily from the contribution of speech-language therapists, occupational therapists, rehabilitation engineers and technicians. Our field's view of an interdisciplinary team has been shaped by the medical model and by relating to augmentative communicators as

clients. We have much to learn from the best in education, developmental psychology, cognitive science and from models that give increasing responsibility to augmentative communicators and their families.

Having been trained as a primary specialist, I value highly an approach to learning that concentrates upon a rich and stimulating environment within which the child can explore, experiment, select, initiate and learn in his/her own way and in which structure is provided sensitively, adapting to the needs of the child. More and more, I am fascinated with the cognitive and language development of young speaking children. I see a strong need to construct different but parallel learning opportunities for nonspeaking children that takes into account the total development of the child. In future years, I look to the field of augmentative and alternative communication to place high value upon unique ways of communicating and to support learnings that allow augmentative communicators to communicate in the manner best suited to their own capabilities.

As our knowledge grows, I await a deeper understanding on the part of professionals as to the ways different individual's process, encode and retrieve information and a greater acceptance of individualized communication systems. I long for the widespread recognition of the need for varied instructional approaches designed to meet the differing learning styles of individuals. This we attempted to do in the early seventies, but we were busy 'doing' and not 'writing' and our experience is not easily accessible to new, young professionals. To-day I see a movement toward quick and easy solutions — relying upon technology

to work the magic. I hope we will find ways to blend the teaching of the seventies with the technology of the eighties.

My work with Blissymbolics has given me a high regard for the structural capabilities offered by a communication system or language. I have many times over, witnessed the self-assurance and the power to initiate and innovate that a communication system provides. From observing the growing years of many young augmentative communicators, I have witnessed the stages through which they pass and the differing communication needs they experience. I have great respect for the various devices and ways of storing and retrieving information and I recognize that individuals may wish to change these aspects of their communication system as they mature. I believe, however, that much caution is needed, regarding changes in an individual's representational system — the graphics component in augmentative communication. It provides the structure through which individuals perceive their worlds and through which they process information. Hopefully, changes are directed by the individual, and are not imposed by others.

I have found it useful to ask three questions when evaluating an individual's communication and representational system:

- Does the user's system strengthen and enhance his/her communication, cognitive, language, social and learning capabilities?
- Has the system been introduced and learned in a way that gives the user a sense of ownership and control?
- Can the user's system grow with him/her?

My questions originate from work with children, but I believe they can be applied constructively to all age levels. As more and more augmentative communicators answer in the affirmative, so we will be meeting my aspirations for our field.

I have been asked to identify ten events which I would nominate for an Order of Merit if we had one. An interesting way to disclose one's biases!

•1971 - the first application of Blissymbolics as a complement or substitute for speech at the Ontario Crippled Children's Centre, Toronto, Canada.

Important then and now, because it offers a system, rich in learning and strategy opportunities to help compensate for the lack of speech.

•1964-1973 - the Non-Oral Communication Project at Iowa University Hospital School, Iowa, U.S.A.

Important in providing a rationale and structure to the development of communication boards in the early years of augmentative communication.

•1973 - a paper in *Journal of Speech and Hearing Disorders*, Vol. 38, #1, February, "Communication Boards for Cerebral Palsied Children" by E. T. McDonald and A. Schultz.

Important because it provided the first published article relating to word boards.

•1975 - workshops in Boston, Chicago and Los Angeles and accompanying Manual - organized by the Trace Centre, Madison, Wisconsin, under the leadership of Gregg Vanderheiden.

Important because it provided a structure for the examination of technology - encoding, direct selection, scanning - and it disseminated information for the first time to professional leaders across the U.S.A. It also provided a forum for demonstration of the Autocom - first device (designed at the TRACE Centre) to respond to the capabilities of the user rather than require the user to be trained to the device.

•1980-1983 - activities (two international conferences in Toronto, 1980, 1982) leading up to the formation of ISAAC in Lansing, Michigan, 1983.

Important because it gave our field an international organization for information exchange and support worldwide.

•1982 - article in *Byte*, September, Volume 7, #9, "Minspeak" by Bruce Baker.

Important because it introduced the concept of semantic compaction and offered a new way of storing and retrieving synthetic speech that did not require that the learner have knowledge of traditional orthography to encode words and phrases.

•1985 - initiation of journal *Augmentative and Alternative Communication* (AAC), published by Williams and Wilkins.

Important because it gave our field a refereed publication, to encourage and report research and to support clinical documentation.

•1986 - Cardiff ISAAC Conference

Important because it provided the first international conference of ISAAC hosted out of North America.

Valuable because of David Crystal's opening address, the quality of the conference and the strengthening of information exchange between Europe and North America.

•1980's - the introduction of synthetic speech on communication devices.

Important because it provided the speech mode within augmentative communication. This capability offers a critical challenge to our field - to identify each individual's best way to learn, store, retrieve and apply words, phrases and larger bodies of information.

•1989 - Forum article in AAC, Volume 5/Number 2, June, "Toward a Definition of Communication Competence for Individuals Using Augmentative and Alternative Communication Systems" by Janice Light.

Important because it offers a preliminary structure for examining communication competence relating to linguistic, operational, social and strategic competencies and their integration. It is essential to have such a structure in order for us to evaluate the effectiveness of our endeavours.

My choice of Order of Merit recipients has been influenced by my need for theoretical frameworks to provide structure to our planning and to allow rationales for our actions. In the past, much has been done and much has been written without reference to a theoretical knowledge base. I hope in the future we'll be able to give much thought to the 'why's of our actions - be they service, research or development focussed.

§

SHIRLEY McNAUGHTON

Augmentative and Alternative Communication: European Perspectives

by Stephen von Tetzchner
and Mogens Hygum Jensen

One of my most valuable discoveries at the ISAAC '96 Conference in Vancouver this August was this new publication. I have long waited for professionals in the AAC field to direct their attention to some of the many theoretical issues we face. With this book, my patience is rewarded!

The contributing authors are all from Europe — providing an excellent opportunity for North American AAC professionals to gain valuable insights into different perspectives. As outlined in the Introduction, the authors offer “a first attempt to establish a distinctive alternative to complement the predominantly behavioural orientation within the field of augmentative and alternative communication”. They are influenced by transactional models of development, the psycholinguistic tradition of studying the mental processes underlying the acquisition and use of language, and social-constructivist models of language and communication. The reader is treated to two main themes: communicative interaction with non-speech communication systems, with an emphasis on linguistic complexity and interaction, and the involvement of parents and professionals in the creation of a language-supportive environment. Both focus on the interactional context.

Throughout the book, there is a search for greater understanding of the communicative and linguistic processes associated with augmentative and alternative communication. For those who have expressed concern regarding the proliferation of AAC practices which lack any theoretical underpinning, this publication is welcome reading, indeed! I am finding myself writing many notes in the margin — delighted to discover ideas that either match my own or stimulate me to respond with a counter position.

One group of chapters of particular interest to me are those relating to intervention planning — recognizing the varying conditions needed for learning by different individuals (Martinsen and von Tetzchner), considering joint attention behaviours (Sarria, Gomez and Tamarit), and examining the dialogue context of aided speakers (von Tetzchner and Martinsen). In the latter chapter, excellent examples are given of the inter-relationship between a child's mode of communication, the parent's adaptations to their child's communication limitations, and the contribution of this parental behaviour to the child's strategies.

Some chapters address the topic of the transition from single-word to multi-word utterances for children using communication boards. Martine Smith describes her clinical experience of children with cerebral palsy using communication boards who demonstrate difficulty in producing multi-symbol utterances disproportionate to their receptive language abilities. She describes a project undertaken by her involving non-disabled preschool children in which their output resembled that of the aided communicators in Smith's clinical experience. She discusses

three possible explanations of her results and suggests the need to consider the effect of the graphic medium.

Hans van Balkom and Marguerite Welle Donker-Gimbrere offer a psycholinguistic approach as a theoretical framework to study graphic language representations in aided communication, and the way in which graphic signs are used in concept formation and message construction. They emphasize the need for a better theoretical basis in order to “understand, explain, improve and evaluate the actual learning strategies of users and the intervention programmes that are supposed to teach such strategies.” Like Smith, they report a small number of graphic signs in the average messages of the graphic sign users with cerebral palsy that they study. The task is to describe a set of pictures as if telling a story to young children. The average is about two graphic signs per message. They discuss the constraints that may be imposed upon graphic sign users by the restricted number of graphic signs available to them. The issues they raise deserve our attention. As the field responds, I hope attention will be given to the different *types* of graphic signs available to graphic sign users.

You will notice that I have been using graphic *sign* instead of the term more commonly used in North America - graphic *symbols*. The rationale can be found in the Introduction, page 10. A notational system is also suggested and used consistently throughout the book.

Excellent reading!

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Co-editors:

Peter Lindsay & Shirley McNaughton

Associate Editors:

Suzanne Clancy, Robert Haaf, Paul Marshall, Nola Millin, Brian Pamplin, Tracy Shepherd, Alda Steprans, Geb Verburg.

Editorial aid: Barbara Reid

Administrative Assistance: Bob McNaughton

Subscriptions: Liz Goldstein

Desk Top Publishing: Shirley McNaughton

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Direct correspondence regarding

subscriptions, articles, advertising, subscription support, address changes and bulk mailing to:

Communicating Together

Suite 215, 3-304 Stone Rd. West
Guelph, Ontario, Canada N1G 4W4
Phone enquiries: 519-766-1757
Fax: 519-763-6682
Email: plindsay@oise.on.ca
smcnaughton@oise.on.ca

Second Class Mail Registration No.7093

Cover: Ann Running with her brother Tim — Two Generation-Xers celebrating! (Celebrating 30ths, p. 7)

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